



## What is it?

### Points To Remember About Paget's Disease

- Paget's disease causes bones to grow too large and weaken.
- The disease is more common in older people and those of northern European heritage. Men are more likely than women to have the disease.
- Signs and symptoms can include pain, enlarged and broken bones, and damaged cartilage in joints.
- Doctors are not sure what causes Paget's disease. They think that a virus may cause it in some cases. It also tends to run in families.
- Doctors usually diagnose Paget's disease with x-rays.
- Paget's disease is treated with medicines, diet, exercise, and surgery. Following a doctor's treatment plan may lower the chance of major changes in your bones.

Paget's disease is a disorder that causes bones to grow too large and weaken. You can have Paget's disease in any bone in your body, but it usually affects the:

- Spine.
- Pelvis.
- Skull.
- Leg bones.

The changes of bone tissue causes affected bone to weaken leading to:

- Bone pain.
- Misshapen bones.
- Fractures.
- Arthritis in the joints near the affected bones.

Paget's disease usually only affects one bone or several bones, but it does not affect the entire skeleton.

## Who gets it?

The disease is more common in older people and those of northern European heritage. Men are more likely than women to have the disease. Research suggests that a close relative of someone with Paget's disease is more likely to develop the disease than someone without an affected relative.

## What are the symptoms?

Many people do not know they have Paget's disease because they have only mild symptoms. For others, signs and symptoms can include:

- Pain.
- Enlarged bones.
- Broken bones.
- Damaged cartilage in joints.

If you have Paget's disease in your leg bones, you may also have bowed legs. Your spine might curve if the disease is in the bones of the spine.

People with Paget's disease in the bones of the skull sometimes have:

- Headaches.
- Hearing loss.
- Large head size.

Symptoms get worse slowly, and the disease does not spread to other bones.

## What causes it?

Doctors are not sure what causes Paget's disease. They think that a virus may cause it in some cases. It also tends to run in families.

## Is there a test?

Doctor's diagnose Paget's disease with x-rays. Your doctor may also order:

- A blood test to check for alkaline phosphatase, an enzyme. People with Paget's disease have too much of this enzyme.
- A bone scan that can show which bones are affected by the disease.

In rare cases your doctor may perform a bone biopsy. During this test, the doctor removes a small sample of bone and looks at it under a microscope.

## How is it treated?

Your doctor treats Paget's disease with:

- Medicine.
- Surgery.

### Medicine

Your doctor may prescribe one of the following medicines to treat Paget's disease:

- Bisphosphonates. These medicines help relieve pain and keep the disease from getting worse.
- Calcitonin. This is a hormone made by the thyroid gland. It may be used for certain patients but it does not work as well as bisphosphonates and is not used as often.

### Surgery

You may need surgery to treat:

- Broken bones, for example your doctor may need to set a broken bone.
- Malformed bones for example your doctor may need to straighten bones to try and lower pain in your joints.
- Severe arthritis, your doctor may recommend you have a knee or hip replacement if medicine and physical therapy do not help.

## Who treats it?

The doctors who treat Paget's disease can include:

- Endocrinologist, a doctor who specializes in hormonal and metabolic disorders.
- Rheumatologist, a doctor who specializes in joint and muscle disorders.
- Orthopedic surgeon, a doctor who specializes in bone injuries and disease.
- Neurologist, a doctor who specializes in brain and nerve disorders or problems.

- Otolaryngologist, a doctor who specializes in ear, nose, and throat disorders.

## Living With It

If you have Paget's disease, the outlook is usually good. When you follow your doctor's treatment plan, you may lower the chance of major changes in your bones. Treatment can help you manage your symptoms but does not cure the disease.

## Healthier Bones

It is never too early or too late to take care of your bones. There are many things that can help you improve your bone health:

- Eat a well-balanced diet rich in calcium and vitamin D. Good sources of calcium include:
  - Low-fat dairy products.
  - Foods and drinks with added calcium.
- Good sources of vitamin D include:
  - Egg yolks.
  - Saltwater fish.
  - Liver.
  - Milk with vitamin D.

Some people may need to take nutritional supplements in order to get enough calcium and vitamin D.

- Get plenty of physical activity. Like muscles, bones become stronger with exercise. The best exercises for healthy bones are strength-building and weight-bearing, such as:
  - Walking.
  - Climbing stairs.
  - Lifting weights.
  - Dancing.

Try to get 30 minutes of exercise each day. Before starting a new exercise plan, talk with your doctor.

## Maintain a Healthy Lifestyle

- Live a healthy lifestyle. Don't smoke, and, if you choose to drink alcohol, don't drink too much.
- Maintain a healthy weight is particularly important if Paget's has led to arthritis of the weight-bearing joints, such as the hip or knee. Excess weight can mean more stress—and pain—for affected joints.
- Prevent falls by:
  - Checking your home for dangers like loose rugs and poor lighting.
  - Installing grab bars and hand rails.
  - Using nonskid mats in the bathroom and tub.

- Seeing your doctor regularly to have your vision checked.
  - Increasing your balance and strength by exercising every day.
- Seek support. It is important to take care of your physical and mental health. Living with Paget's disease can be stressful. You may find it helpful to speak to:
  - Social workers.
  - Counselors.
  - Mental health professionals.
  - Other people with the disease.

Your doctor can help you find counselors or a support group.

## Other Medical Problems

Paget's disease can lead to other medical problems, such as:

- Arthritis.
- Hearing loss.
- Heart disease.
- Kidney stones.
- Curve on the spine.
- Brain or spinal cord problems.
- Loose teeth.

Rarely, people with Paget's disease can have:

- Bone cancer.
- Vision loss.

## For More Info

### **U.S. Food and Drug Administration**

Toll free: 888-INFO-FDA (888-463-6332)

Website: <https://www.fda.gov>

[Drugs@FDA](https://www.accessdata.fda.gov/scripts/cder/daf) at <https://www.accessdata.fda.gov/scripts/cder/daf>. [Drugs@FDA](https://www.accessdata.fda.gov/scripts/cder/daf) is a searchable catalog of FDA-approved drug products.

### **Centers for Disease Control and Prevention, National Center for Health Statistics**

Website: <https://www.cdc.gov/nchs>

### **NIH Osteoporosis and Related Bone Diseases ~ National Resource Center**

Website: <https://www.bones.nih.gov>

### **American Academy of Orthopaedic Surgeons**

Website: <http://www.aaos.org>

**American College of Rheumatology**

Website: <http://www.rheumatology.org>

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